Autism and marginalised communities

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Focus of the talk

☐ Understanding experiences of marginalised individuals effected by autism

☐ Considering some of the challenges for individuals, family members and service providers
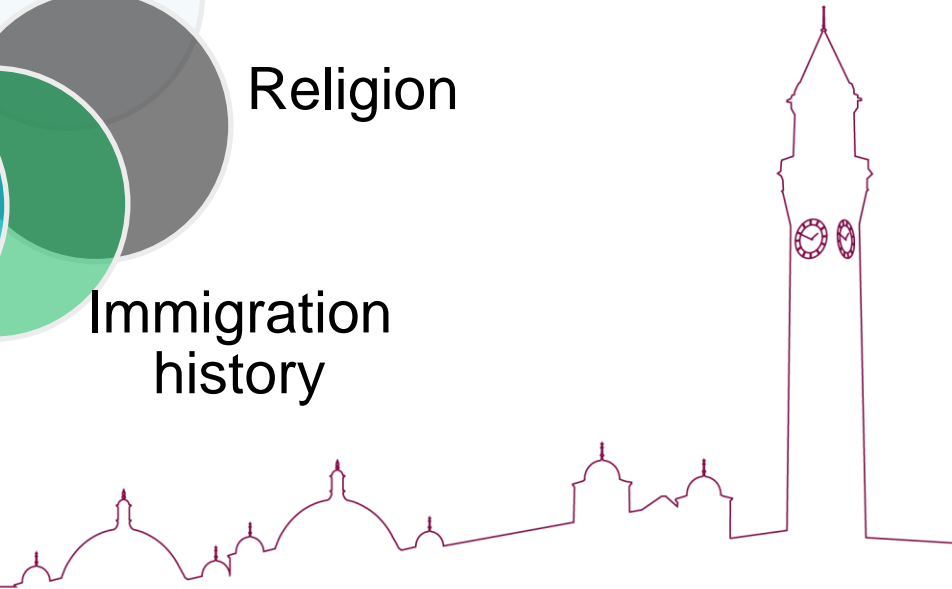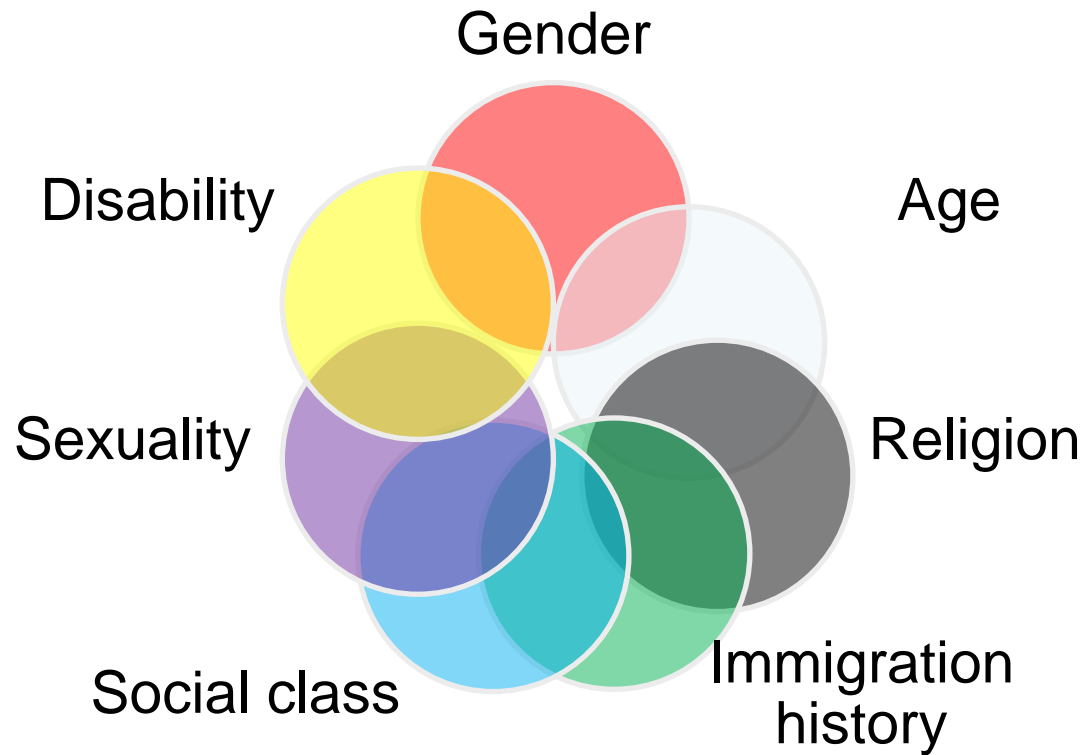
☐ Sharing some examples of good practice
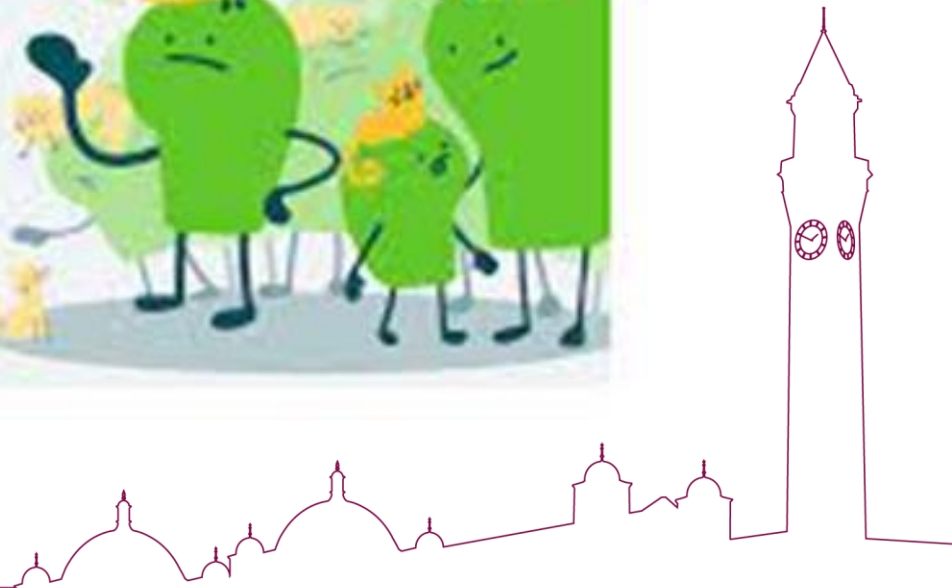
Autism research

☐ Autism occurs in all communities

☐ Prevalence rates are increasing

☐ It is important to follow good autism principles

Multiple human identities

Gender

Disability

Age

Sexuality

Religion

Social class

Immigration
history

Lack of research

Who is marginalised?

☐ Families from minority ethnic communities

☐ When English is on their first language

☐ Those who are from lower-economic backgrounds

☐ Children in care system

Interplay of factors

☐ Differences in autism prevalence based on ethnicity, language and economic status (Roman-Urrestarazu et al., 2021, Perepa et al., 2023)

☐ SEND, economic background and ethnicity impacts educational experiences (DfE, 2018; Graham et al., 2019, Guldberg et al., 2020)

Questions to reflect on

- [ ] Is your service accessed by everyone in your community?

- [ ] Do you ever consider the impact of disadvantages in relation to autism?
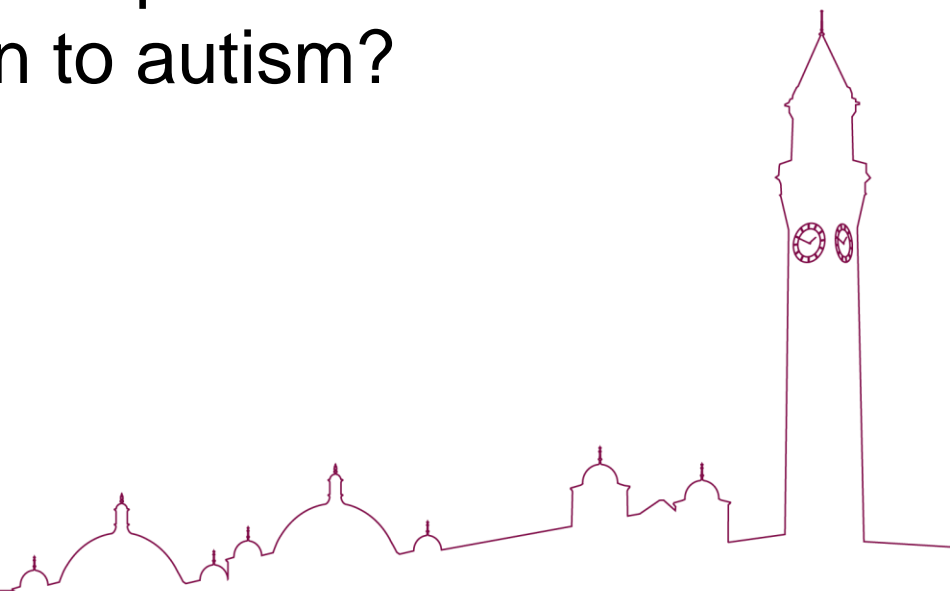
Barriers experienced by families

☐ Language differences, lack of translation

☐ Being misunderstood or judged by school/professionals

☐ Lack of professional knowledge

☐ Own previous experience or that of their child

Access to diagnosis and services

- ☐ *"When I call up places to get him his therapies they tell me there is a nine month waiting list and then they say, well actually you can't go on the waiting list as you don't have a diagnosis from England."* **Parent**

- ☐ *"Some parents may not have access to a wide range of information or have self-advocacy skills which can then lead to being unable to identify and advocate for the best outcomes for their child."* **Local authority staff**

Family experiences

☐ Lack of proper resources

☐ Lack of professional support

☐ Fears of not being understood or accepted

☐ Not knowing how to navigate UK systems

☐ Lack of community support

Parent/carer experiences

- *"The LA came up with options for my school to go to. But it was very hard to know what we were looking for and nobody gave me advice. I was left to figure this out myself."*

- *"I am aware that there is a risk that certain conscious or unconscious biases may seep down from teaching staff. There are differences in teachers picking up dyslexia for example between different races. When it came to his dyslexia application, I was like can you see what I see. But they tended to ignore it."*
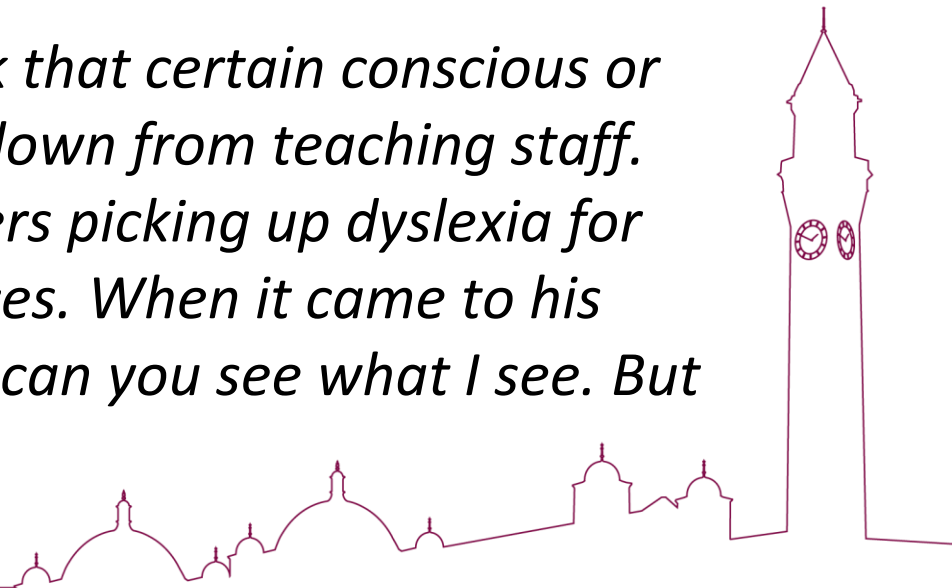
Finances and engagement

☐ *"Sometimes you may have the phone call to say that your child has been excluded and so you aren't able to work for the next however many days that child has been excluded for or that even this idea of reduced timetables. For a phased transition into a school, it is accepted as good practice within the SEND code of practice that for six weeks. That can be very, very difficult for parent and their work."*

☐ *"Some may be in hostels and have no privacy. There is a great difficulty when their children are loud, distressed or overloaded. Neighbours will complain. We have many families with really difficult situations with neighbours because the amount of noise their children make. Neighbours can become abusive. Families feel isolated from their community because they get a lot of negative attention."*
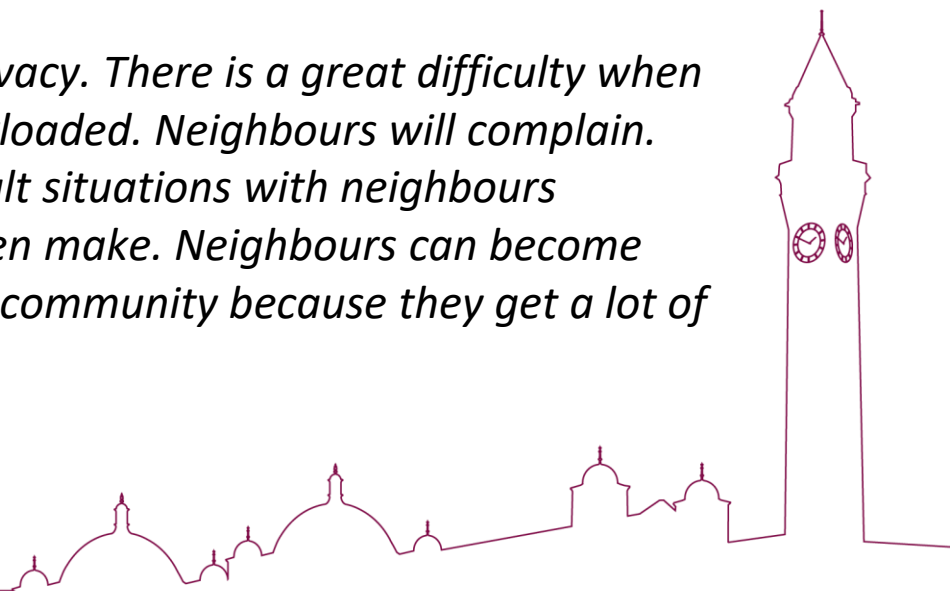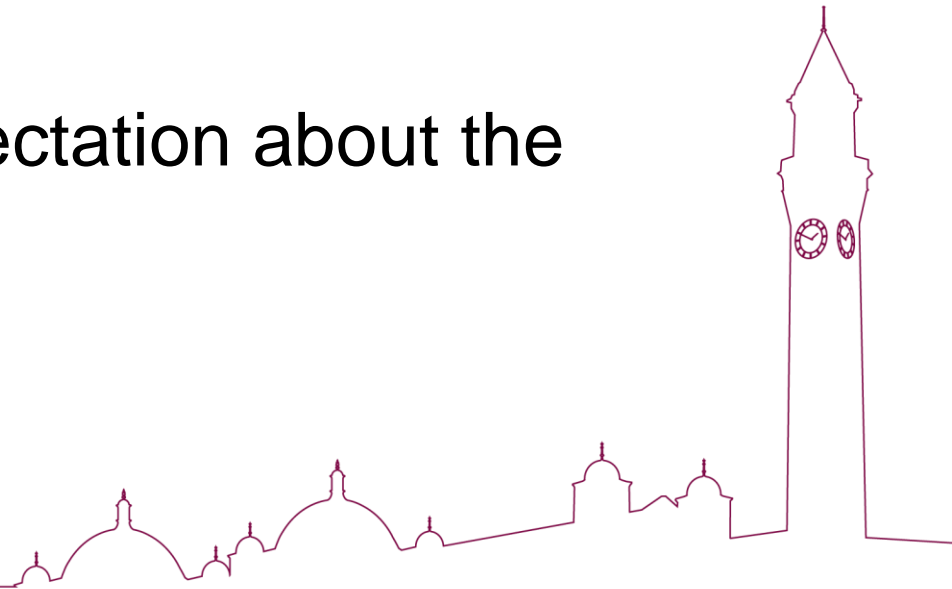
Challenges for professionals

- Parental disengagement

- Language barriers

- Differences in expectations

- Breakdowns in communication

- Cultural barriers
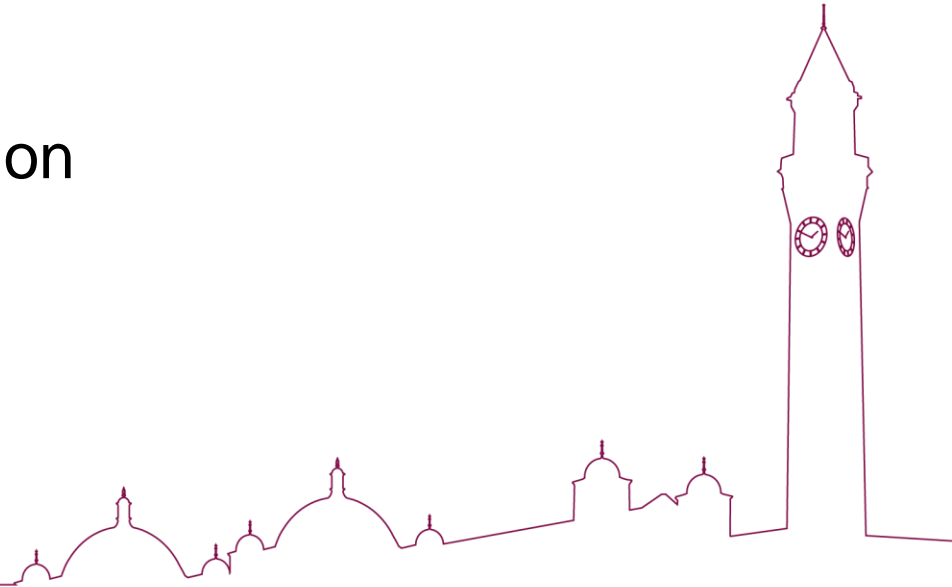
- Financial cuts to services

- Lack of teacher time

- Lack of training

- Outside agencies expectation about the curriculum and results

Examples of best practice

- ☐ Regular contact at convenient times
- ☐ Resources for home
- ☐ Supporting/advocating for them with other services & benefits
- ☐ Translation/interpretation
- ☐ Friendly, approachable, empathic
- ☐ Networks to link with other parents
- ☐ Learning and understanding family context
- ☐ Offering 1:1 tuition
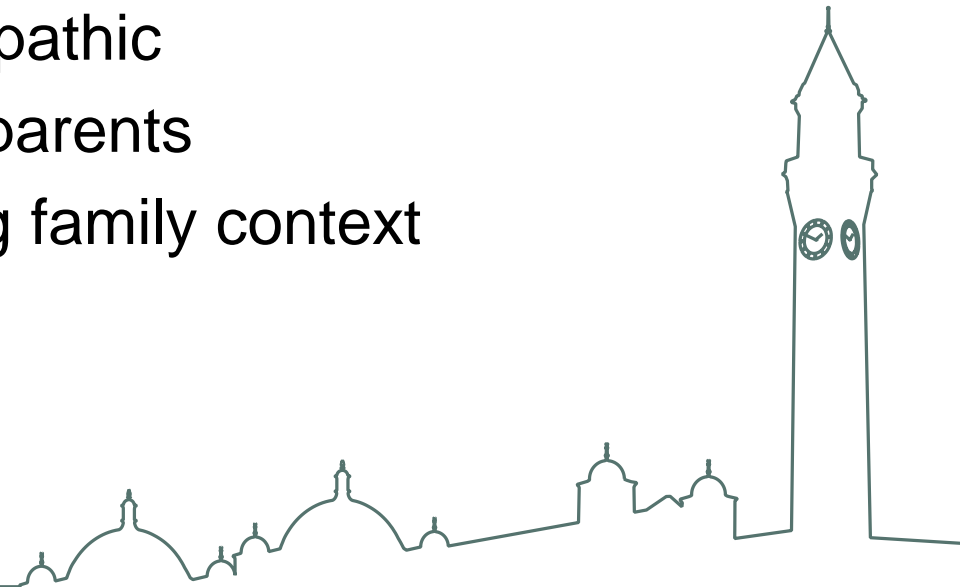
Culture, autism and identity

☐ Language and social expectations

☐ Stigmatisation can impact self-esteem

☐ Masking or trying to blend

☐ Co-relation between identity and mental health (Umaña-Taylor and Updegraff, 2007)

☐ More likely to be referred by compulsory routes (Edbrooke-Childs and Patalay, 2019)
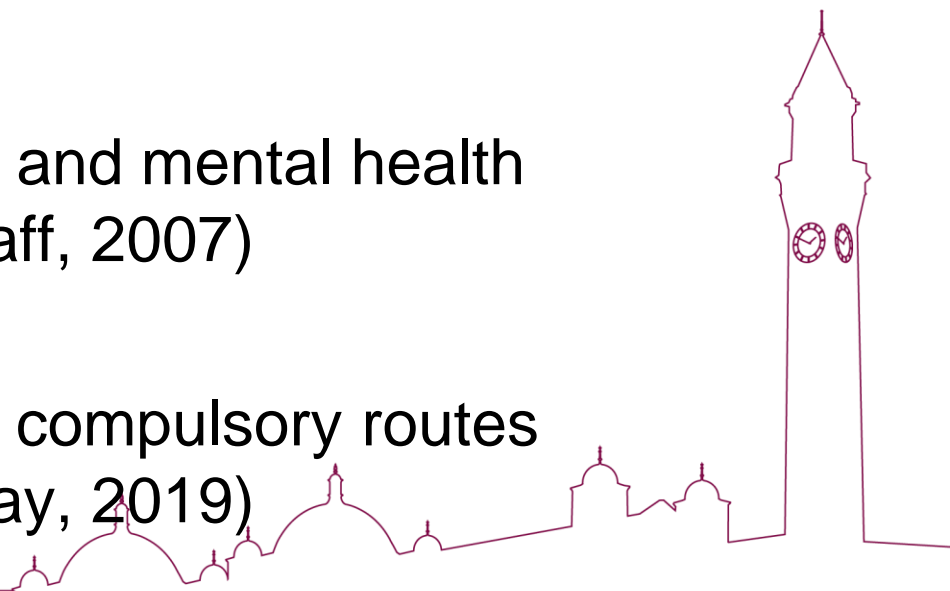
When working with the individual

☐ Being aware of individual identity

☐ Providing opportunities to develop positive cultural and linguistic identity

☐ Developing appropriate social and life skills

☐ Listening to what the individual says